Developmental / Epileptic Encephalopathy with Spike Wave Activation on Sleep (DEE-SWAS)

What Is DEE-SWAS?

DEE-SWAS is a rare type of epileptic encephalopathy. In 2022 the International League Against Epilepsy updated the nomenclature of several childhood epilepsy syndromes and now the term DEE-SWAS includes a spectrum of conditions characterized by cognitive, language and behavioral symptoms. Patients with Landau-Kleffner syndrome, atypical benign partial epilepsy (pseudo-Lennox syndrome) and epilepsy with continuous spike-wave during sleep (CSWS) or electrographic *status epilepticus* of sleep (ESES) are now classified as having DEE-SWAS.

Children with the condition will have:

- Different types of seizures
- Variable degrees of language and cognitive regression
- Behavioral issues
- Spike-wave activation during sleep on EEG

DEE-SWAS begins between 2 - and 12-years-old, and the course of the disease is variable. Antiseizure medication often controls seizures; but language, cognitive, and behavior issues are more difficult to treat. EEG usually improves during adolescence and is accompanied by cognitive and behavioral improvement.

What Kinds of Seizures Happen in DEE-SWAS?

There are different seizure types in DEE-SWAS. They can cause a variety of symptoms.

Focal seizures:

In this type of seizure, a child:

- Has rhythmic jerks (clonic movements) in one part of the body
- Stares and is unresponsive

This type of seizure can also evolve to a convulsion (bilateral tonic-clonic seizure)

Tonic-Clonic Seizures

In this type of seizure, a child:

- Has convulsions, or rigid muscles and rhythmic body jerks
- Rolls the eyes back
- Cries out
- May pee or poop
- Can't respond during seizure
- Is confused and sleepy after the seizure

What Causes DEE-SWAS?

DEE-SWAS can be caused by multiple conditions such as genetic mutations, brain malformations or perinatal injuries. Frequently no specific cause can be identified.

How Is DEE-SWAS Diagnosed?

A pediatric neurologist (a doctor who treats brain, spine, and nervous system problems) can diagnose the condition by doing tests such as:

- EEG
- VEEG, or video electroencephalography (EEG with video recording)
- MRI

How Is DEE-SWAS Treated?

Seizures in DEE-SWAS are treated with antiseizure medications. Some patients may need steroids.

How Can Parents Help?

Caring for a child with DEE-SWAS can be challenging. Work with your child's care team to set up medical visits, therapies and a treatment plan that provides your child with a good quality of life.

Make sure that you and other adults and caregivers (family members, babysitters, teachers, coaches, etc.) know what to do during a seizure. Because it could lead to a generalized tonic-clonic seizure, your doctor may prescribe an emergency medication to give if your child has a long seizure or many seizures in a short amount of time. Be sure to ask your doctor about a seizure rescue plan for your child.

What Else Should I Know?

If your child has epilepsy, your doctor and the care team can answer questions and offer support. They also might be able to recommend a local support group. Online organizations can help too, such as:

- Epilepsy Foundation
- CDC – Managing Epilepsy